

## **Patient and caregivers self-care needs in relation to heart failure: developing guidance for patient care in the community**

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*Publication date:*  
2012

*Document Version*  
Publisher's PDF, also known as Version of record

[Link to publication in ResearchOnline](#)

*Citation for published version (Harvard):*  
Currie, K 2012, *Patient and caregivers self-care needs in relation to heart failure: developing guidance for patient care in the community*. The Queen's Nursing Institute Scotland.  
<<http://www.qnis.org.uk/resources/project-reports/>>

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## **Final Project Report: EKSCH01**



### **Patient and caregivers' self-care needs in relation to heart failure: Developing guidance for patient care in the community.**

**August 2012.**

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## CONTENTS

<b>1.0 EXECUTIVE SUMMARY .....</b>	<b>3</b>
1.1 Aim and objectives:.....	3
1.2 Methodology: .....	3
1.3 Key findings:.....	3
1.4 Conclusions .....	4
1.5 Implications for Practice .....	4
1.6 What next .....	5
<b>2. 0 BACKGROUND: .....</b>	<b>6</b>
2.1 AIMS & OBJECTIVES: .....	6
<b>3.0 METHODOLOGY: .....</b>	<b>7</b>
3.1 Conceptual Definitions:.....	7
3.2 Review method: .....	7
<b>4.0 FINDINGS: .....</b>	<b>7</b>
4.1 Key messages from findings: .....	9
<b>5.0 RECOMMENDATIONS FOR PRACTICE:.....</b>	<b>10</b>
<b>6.0 LESSONS LEARNED &amp; WHAT WE WOULD DO DIFFERENTLY .....</b>	<b>11</b>
6.1 Use of Joanna Briggs Evidence Synthesis Software: .....	11
6.2 Consultation with patients and caregivers: .....	11
6.3 International collaboration:.....	11
<b>7.0 CONCLUSIONS: .....</b>	<b>12</b>
<b>8.0 DISSEMINATION PLAN: .....</b>	<b>13</b>
<b>9.0 FUTURE DEVELOPMENTS/ NEXT STEPS.....</b>	<b>14</b>
<b>10.0 PERSONAL DEVELOPMENT:.....</b>	<b>14</b>
<b>11.0 FINANCIAL REPORT .....</b>	<b>16</b>
<b>12. REFERENCES .....</b>	<b>17</b>
<b>APPENDIX 1: .....</b>	<b>18</b>
Self- care needs in heart failure: Feedback from Scottish service users. ....	18
<b>APPENDIX 2: Steering Group Members: .....</b>	<b>20</b>

## 1.0 EXECUTIVE SUMMARY

### 1.1 Aim and objectives:

The overall aim of this project was to improve community nursing practice in relation to promoting and supporting effective self-care for patients who live with chronic heart failure in the community.

The project objectives were to

- a) Systematically conduct a robust review and meta-synthesis of qualitative research evidence. The aim of the systematic review was to 'understand heart failure self care in terms of patients *own* self-care management techniques and how elements of *context* affect heart failure self care, identifying the *causal barriers and facilitators* of self care *actions*.'
- b) Use the outcomes of that synthesis to create guidance which would be incorporated into educational provision for professionals working in the field of heart failure; specifically the Specialist Community Nursing programme and community based Heart Failure Nurse Specialist programmes delivered nationally by Glasgow Caledonian University, with wider dissemination to other community practitioners involved in heart failure management.
- c) Provide a professional development opportunity for a community nurse to engage in systematic review, evidence synthesis and practice guidance development.

### 1.2 Methodology:

Meta-synthesis of qualitative research findings from 45 studies (1995-2010) using Joanna Briggs Institute software systems and techniques.

### 1.3 Key findings:

The evidence indicates that formal knowledge does not necessarily lead to better self-care, as patients often report knowing 'what' they ought to do, yet have difficulty knowing 'how' to integrate this knowledge in their daily lives. In addition, research points to persistent misunderstandings or misconceptions held by patients. Similarly, individuals' attitudes, beliefs and personal values also influence their interpretation of self-care advice. Thus, self-care is not simply a matter of adequate knowledge; it is a complex social process, enacted in a variety of contexts, and influenced by a wide range of factors.

Cognitive function, specifically mild cognitive impairment, and mental health issues such as depression are also identified by patients as affecting their ability to engage in self care.

Informal caregivers provide a significant role in supporting patients, yet the evidence indicates that they may be an underutilised resource in planning self-care management; where appropriate, involving caregivers in consultations and information provision is likely to enhance self-care effectiveness.

Other social networks and mechanisms, such as self-help groups or patient forums also provide a valuable means of support for individuals to develop knowledge and skills in self-care in heart failure.

Health professional support for self-care requires an appreciation of the individual, the complexity of their circumstances and the provision of tailored practical information and advice; simply imparting formal knowledge or instructions may not result in the desired outcome.

#### **1.4 Conclusions**

This meta-synthesis provides internationally derived evidence which suggests that effective self-care emerges from the complex interplay of individual and contextual factors; engaging in self-care is a value-laden, social process, which requires more than information transmission via health professionals to enable participation.

The pivotal nature of health professional support and advice has been highlighted within this study; arguably, effective communication with health care professionals may be as significant as clinical aspects of care in influencing patient outcomes.

Health professionals should seek to provide helpful information and practical solutions which acknowledge and address the individuals' circumstances and abilities, sharing learning from successful and less successful experiences of other patients. To do this, health professionals must establish constructive relationships with patients, listening to their individual concerns, and demonstrating respect and reciprocal communication.

#### **1.5 Implications for Practice**

- As part of the routine care plan, designated health professionals should formally and regularly assess patients for problems that might affect their ability to organize their self-care, for example
  - Any cognitive impairment, such as difficulty concentrating or problems remembering to do things
  - Depression
  - Excessive tiredness / fatigueand should then tailor their advice to deal with these problems.
- In relation to patient education, health professionals should;
  - Listen to patients to identify their priorities and daily challenges
  - Provide easily understood information about all aspects of self care in heart failure
  - Share 'know how' ideas for managing self-care in their daily life (drawn from suggestions other patients find helpful)
  - Check that patients understand the advice

- With the agreement of patients, health professionals should involve carers (family or friends who provide help or support) in discussions about treatment where possible, particularly in relation to when and how to seek professional help
- Health professionals should encourage patients and carers to maximize opportunities for social support, for example by getting involved in support groups

### **1.6 What next**

The recommendations from this study have been integrated into educational provision for undergraduate nurses, community based Heart Failure Specialist Nurses and Practice Nurses at Glasgow Caledonian University. Further dissemination via publication, conference presentation, and stakeholder networks is planned.

Findings from this study will be used as a springboard for further international collaborative projects aiming to promote self-care in heart failure, within a community context.

## 2.0 BACKGROUND:

Chronic heart failure is an extremely common and burdensome syndrome that affects a growing number of people around the world. In keeping with contemporary models for the management of long term conditions, the primary goal in caring for people who have heart failure is to promote self-management in order to optimize community living and avoid hospital admission as far as possible<sup>1</sup>; the role of specialist heart failure nurses who monitor and manage complex patient care in the community, and increasingly practice nurses who provide self-management advice in the clinic setting, are pivotal to achieving this goal.

Whilst there is an extensive body of literature related to self-care in heart failure, there have been no previous syntheses of research into patient and caregivers' perspectives on self-care needs. Therefore, existing knowledge remains underutilized in current educational and health care programs and specialist community nursing practice; synthesising available knowledge and generating evidence based guidance based on this synthesis should improve the responsiveness and appropriateness of professional support offered around patient and caregiver self-care needs. More specifically, knowledge from this synthesis could be incorporated directly into the education of community based health professionals and disseminated widely to inform community nursing practice, thus improving the health of people living with heart failure in the community.

This paper reports the outcomes of a meta-synthesis of qualitative research, conducted in collaboration with academic and community practice colleagues in the UK and Canada, providing a local, national and international dimension to the work.

### 2.1 AIMS & OBJECTIVES:

The overall aim of this project was to improve community nursing practice in relation to promoting and supporting effective self-care for patients who live with chronic heart failure in the community.

The project objectives were to

- a) Systematically conduct a robust review and meta-synthesis of qualitative research evidence. The aim of the systematic review was to 'understand heart failure self care in terms of patients *own* self-care management techniques and how elements of *context* affect heart failure self care, identifying the *causal barriers and facilitators* of self care *actions*.'
- b) Use the outcomes of that synthesis to create guidance which would be incorporated into educational provision for professionals working in the field of heart failure; specifically the Specialist Community Nursing programme and community based Heart Failure Nurse Specialist programmes delivered nationally by Glasgow Caledonian University, with wider dissemination to other community practitioners involved in heart failure management.
- c) Provide a professional development opportunity for a community nurse to engage in systematic review, evidence synthesis and practice guidance development.

### 3.0 METHODOLOGY:

#### 3.1 Conceptual Definitions:

Self-care can be defined as “The decisions and strategies undertaken by the individual in order to maintain life, healthy functioning and well-being.”<sup>2</sup> Self-care is also described as a naturalistic decision-making process involving knowledge, experience, skill, and compatibility with personal values.<sup>3</sup> For the purpose of this synthesis, we drew on a taxonomy of ‘needs’<sup>4</sup> to define a ‘heart failure self-care need’ as: *a lack of something wanted or deemed necessary for effective heart failure self-care by patients, caregivers or by research*. Accordingly, heart failure self-care needs can be:

- *Normative* (i.e. needs that are interpreted reasonably in the light of research to constitute needs whether identified or not by the patient or lay caregiver)
- *Felt* (i.e. needs that are perceived wants, wishes, and desires of the patient or lay caregiver)
- *Expressed* (i.e. vocalized needs by the patient or lay caregiver)

The theoretical approach informing this review was that of critical realism; briefly, critical realism is a theory that points to the importance of understanding how individual and contextual factors come together in complex ways to influence human behaviour and outcomes.<sup>5,6</sup> Qualitative research methods are those best suited to examining the complexities of self-care processes and behaviours as they occur in natural settings and can capture the ‘insider’ perspectives of those most closely involved around felt or expressed needs while allowing interpretations of normative needs.

#### 3.2 Review method:

The project adopted a recognised meta-synthesis approach,<sup>7</sup> the purpose of which is to identify and re-analyse qualitative studies, comparing findings in light of each other to generate new knowledge. As a condition of project funding, the study protocol was registered with the Joanna Briggs Institute (JBI Protocol 472), a global collaborative network which aims to ensure robust peer-review of systematic meta-synthesis work entered onto a dedicated software system (JBI QUARI). Further detail of the study methodology is provided within this registered protocol, available at <http://connect.jbiconnectplus.org/ViewSourceFile.aspx?0=4682>

### 4.0 FINDINGS:

A detailed search strategy was applied to a range of publication databases, in order to locate relevant qualitative research studies published between 1995-2010. The initial search strategy returned 1,086 papers; screening of titles highlighted 235 potentially relevant articles; further evaluation of the abstract identified 51 studies, which were entered onto JBI QUARI software for independent quality assessment and extraction of findings by two researchers; 45 studies were included in the final meta-synthesis.

In keeping with the theoretical framework of critical realism, our review sought to synthesise findings related to the *individual; context; and human behaviour (strategies)* in relation to recognised *self-care domains*. Table 1 below presents a summary of findings presented as key components within each of the synthesised categories of the theoretical framework; it can be seen that several facilitators and barriers appear influential in relation to more than one component of self care, particularly in relation to patient and caregiver knowledge, and relationships with health care providers.



**Table 1: Summary findings from systematic review of self-care need in heart failure.**

<b>Synthesised category</b>	<b>Components</b>	<b>Barriers</b>	<b>Facilitators</b>
<b>Domains of self-care need:</b> <i>Factors identified by guidelines as constituting self-care of HF</i>	Medication Diet Fluids Help-seeking Smoking Physical activity Maintaining independence	Low formal knowledge, especially medicines & fluid management. Forgetfulness and misconceptions. Challenges of the regimen. Competing demands. Fear of hospitals. Poor relationship with health care provider.	Good formal knowledge / Connecting symptoms experienced to HF. Making self-care 'routine'. Daily cues and reminders. Experiencing the threat of symptoms and hospitals. Good relationship with health care provider.
<b>Individual:</b> <i>Factors which reside in the individual</i>	Formal and informal knowledge Patient beliefs and attitudes Self-efficacy Learning and experience Skills Cognitive impairment Mental health	Low formal knowledge / understanding of links between HF & symptoms. Negative beliefs & misconceptions. Co-morbid illnesses. Lack of HF management routine. Forgetfulness. Anxiety and depression.	Good formal knowledge / Connecting symptoms experienced to HF. Positive attitudes. Intrinsic motivation / willingness to adhere. Coherent framework for management e.g. memory cues. Sense of control over condition. Learning from experience.
<b>Contextual:</b> <i>Factors external to the individual</i>	Health care team Support groups Caregivers Social networks Culture Finances Work	Poor communication with health providers. Low continuity of care. Lack of information (for patient and caregiver). Competing demands on caregivers. Peer pressure; negative social influence or isolation. Lack of financial resources. Competing demands from employment.	Good communication with health care providers; effective listening, respect and support. Effective team working & collaboration. Effective information and advice (for patient and caregiver). Caregiver presence and action. Developing a repertoire of cues. Support from family / wider social network. Integrating employment and self-care.
<b>Strategies:</b> <i>Coherent, mindful initiatives used by patients to promote effective self-care</i>	Perceptions Actions	Maladaptive coping strategies e.g. denial, ignoring symptoms, binge eating, smoking for stress.	Acceptance of HF. Adjustment of daily tasks & lifestyle. Intensive self-monitoring. External aids for management.

#### **4.1 Key messages from findings:**

This meta-synthesis provides internationally derived evidence which suggests that effective self-care emerges from the complex interplay of individual and contextual factors. Individual elements such as formal knowledge (know 'what') and informal knowledge and skills (know 'how') are vitally important; however, contrary to popular belief, they are not necessarily enough on their own to ensure consistent application of self-care behaviours. Patients' attitudes and beliefs determine the way in which self-care advice is viewed in relation to personal values and the type of life the individual wants to lead. Aspects of context, such as the presence of caregivers; social support; relationships with health care professionals also strongly influence self-care, partly by mediating the influence of individual factors.

The evidence indicates that formal knowledge does not necessarily lead to better self-care, as patients often report knowing 'what' they ought to do, yet have difficulty knowing 'how' to integrate this knowledge in their daily lives. In addition, research points to persistent misunderstandings or misconceptions held by patients, such as not appreciating that 'sodium' is 'salt' or recognising the link between daily weighing and fluid management in symptom control. Some form of 'bridging' from conceptual to actual self-care is needed and health professionals should seek to provide practical solutions which acknowledge and address the individuals' circumstances and abilities, sharing learning from successful and less successful experiences of other patients. To do that effectively, health professionals must establish constructive relationships with patients; this meta-synthesis provides powerful evidence of both helpful and hindering professional behaviours. Poor communication with health professionals was characterised by impersonal, indifferent, overly clinical interactions in which the patients experienced a lack of respect or involvement. Other barriers included low continuity of care, with patients having to consult multiple practitioners who often provided inconsistent advice. Conversely, previous research has highlighted the positive impact of respectful, reciprocal communication, where patients experienced active concern and involvement in their care decisions. Interestingly, access to specialist multidisciplinary teams and social support groups were found to help patients develop knowledge and confidence in their ability to self-care.

The influence of cognitive function, specifically mild cognitive impairment, and mental health issues such as depression are identified by patients as affecting their ability to self care; however, individual assessment and tailored support are not necessarily provided, meaning that the impact of these cognitive and emotional components are not addressed in self-care plans.

Caregivers provide a significant role in supporting patients, yet the evidence indicates that they may be an underutilised resource in planning self-care management; where appropriate, involving caregivers in consultations and information provision is likely to enhance self-care effectiveness.

Supporting self-care requires an appreciation of the individual and their circumstances and the provision of practical information and advice rather than simply imparting formal knowledge or instructions. However, effective self-care should be seen as more than specific knowledge or skills to master; it is inherently a value laden, social process and health professionals should assume that any advice they offer will be interpreted by patients and caregivers in the context of their personal values and circumstances. Effective patient support should seek to harness these social mechanisms, within the context of constructive inter-personal relationships and communication.

## 5.0 RECOMMENDATIONS FOR PRACTICE:

Existing international guidelines already promote self-care as the cornerstone of heart failure management; however the emphasis is frequently on 'what' patients ought to do or the care delivery structures within which this advice should be delivered. The findings from this study challenge these traditional approaches and suggest that effective support for self-care should focus on 'how' health professionals engage with patients and their informal carers, as well as attending to the wider individual and social context in which self-care is managed.

In addition to reconsidering the general approach to promoting self-care, the following points provide a summary of recommendations for current practice, drawn from the evidence reviewed;

- As part of the routine care plan, designated health professionals should formally and regularly assess patients for problems that might affect their ability to organize their self-care, for example

- Any cognitive impairment, such as difficulty concentrating or problems remembering to do things
- Depression
- Excessive tiredness / fatigue

and should then tailor their advice to deal with these problems.

- In relation to patient education, health professionals should;
  - Listen to patients to identify their priorities and daily challenges
  - Provide easily understood information about all aspects of self care in heart failure
  - Share 'know how' ideas for daily life (drawn from suggestions other patients find helpful)
  - Check that patients understand the advice
- With the agreement of patients, health professionals should involve carers (family or friends who provide help or support) in discussions about treatment where possible
- Health professionals should encourage patients and carers to maximize opportunities for social support, for example by getting involved in support groups

## **6.0 LESSONS LEARNED & WHAT WE WOULD DO DIFFERENTLY**

### **6.1 Use of Joanna Briggs Evidence Synthesis Software:**

The trigger for this meta-synthesis study was the recognition that a wealth of qualitative research related to self-care in heart failure existed, yet had not been brought together in a coherent way. However, the project team could not have predicted the volume of qualitative findings or the magnitude of the task of meta-synthesis which would emerge once the project was underway.

In hindsight, we believe that the JBI QUARI software did little to assist and much to hamper the creative re-interpretation of findings in such a complex meta-synthesis as this turned out to be. The team experienced significant practical difficulties with the software, for example, initially findings could only be allocated one category heading, rather than being categorised in as many different ways as was appropriate; these issues were fed-back to the JBI system co-ordinators and eventually led to changes being made to the software programme. However, this caused a delay of several months during 2011 while these changes were being made by JBI. Subsequently, the form of findings entered onto the software by the research team (a summary of the original author's interpretation of their data) produced an excessive volume of data, which the JBI system was unable to present in a coherent way; advice from the JBI co-ordinators was to significantly reduce the volume of findings to a simple theme heading and illustrative quotation. This required complete re-entry of the data from all studies, which had not been costed into project funding and therefore, once again caused significant delay in completing the meta-synthesis on the JBI system. In the meantime, the research team had used manual tables of extracted data to complete the meta-synthesis and generate recommendations for practice; our experience leads us to the view that the JBI software system forces an extremely time-consuming and reductionist approach to meta-synthesis, which was not entirely appropriate for this large project. We would not feel able to recommend use of JBI systems for comparable projects in future.

### **6.2 Consultation with patients and caregivers:**

Findings and recommendations from this project were presented to a meeting of the West of Scotland heart failure patient forum, attended by approximately 75 service users. Following the presentation, members took part in a wide ranging discussion of the recommendations and many volunteered to complete a brief opinion survey (findings summarised in Appendix 1). This was a worthwhile event and provided an excellent service user perspective and 'reality check' on the recommendations, demonstrating the welcome with which the project outcomes were accepted. We would recommend further use of this method of stakeholder engagement in future.

### **6.3 International collaboration:**

This was the first time that this group of Canadian and Scottish researchers had collaborated on a meta-synthesis project; overall, this was a constructive and positive experience for all involved, with communication facilitated via on-line Skype meetings. Based on this effective team-working experience, further collaborations are already in progress.

## **7.0 CONCLUSIONS:**

Overall, the project outcomes were achieved; meta-synthesis of qualitative evidence has demonstrated the complex interplay between individual and contextual factors in presenting enablers and barriers to effective self-care of heart failure by people trying to manage their condition at home. The pivotal nature of health professional support and advice has been highlighted; arguably, effective communication with health care professionals may be as significant as clinical aspects of care in influencing patient outcomes.

Funding from QNIS enabled a Heart Failure Advanced Nurse Practitioner, who supports patients to manage their heart failure in the community, to gain first-hand experience of the various stages of meta-synthesis as a robust method to generate evidence to guide clinical practice. In addition to providing an opportunity to gain valuable academic skills at a personal development level, this experience will be shared with clinical colleagues.

Unfortunately, the use of Joanna Briggs Institute QUARI software was not particularly helpful in the conduct of this project and we would recommend the QNIS Committee consider alternative approaches to maintaining quality control for similar projects in future.

## **8.0 DISSEMINATION PLAN:**

### **Education provision:**

- Project findings and recommendations have already been integrated into the following educational provision at Glasgow Caledonian University:
  - MSc level heart failure specialist nurse module 'Optimal heart failure care'
  - Hon level community nursing module 'Introduction to General Practice Nursing'
  - Undergraduate nursing students within the BN programme module 'Long Term Conditions; Principles of care'.

### **Publications:**

- The full scientific report of the meta-synthesis has been submitted to the Joanna Briggs Institute for peer review.
- A publication strategy has been agreed within the team and work is in progress for submission of six articles to relevant professional journals;
  - HF self care: Knowledge versus understanding; The role of context in influencing HF self care; Skills needed for HF self care; Views and reactions to health professionals and HF programs; Self care strategies of HF pts; Influence of Cognitive Impairment on self-care in HF.

### **Conference presentation:**

- Project methodology was presented as a poster at the International Nursing Intervention Research Conference, Montreal, Canada, in April 2011.
- Project findings and recommendations were presented at the Royal College of Nursing International Research Conference in London, April 2012.
- Project findings and recommendations are to be presented to the Scottish Heart Failure Specialist Nurse Forum in November 2012.
- An abstract has been submitted to the ICCHNR March 2013 conference

### **Stakeholder network dissemination:**

- A summary of the service user opinion survey has been included in the Greater Glasgow & Clyde Cardiac Management Clinical Network newsletter.
- Two posters summarising this work will be available on the QNIS website

## **9.0 FUTURE DEVELOPMENTS/ NEXT STEPS**

The outcomes of this project have generated ideas for future research into developing tailored patient education advice, taking account of the complexity of factors influencing effective self-care, with collaborative grant proposal development planned.

A summary of findings and recommendations will be professionally produced and circulated with a request for further dissemination via their networks to The British Heart Foundation; The British Society for Heart Failure; The Scottish Heart Failure Nurse Specialist Forum; The Scottish Practice Nurse Network.

## **10.0 PERSONAL DEVELOPMENT:**

The following objectives formed the development plan for the community nurse employed part-time on the project:

1. By working with and supporting experienced researchers, gain an understanding of the principles of qualitative systematic review, including

- developing a protocol for qualitative systematic review
- developing a systematic review literature search strategy
- using recognised critical appraisal tools to undertake quality analysis of research literature
- using a structured approach to extracting qualitative data for meta-synthesis
- synthesis of qualitative data
- generating a report

2. Become familiar with the Joanna Briggs Institute database systems for managing qualitative data for systematic reviews by gaining experience of entering data.

3. Participate in an international collaborative working group to develop good practice guidance for practitioners, based on the evidence from the systematic review.

4. Contribute to creating a poster illustrating outcomes of the project.

These objectives were achieved; in addition, the community nurse has continued to work with the lead researcher to contribute to a peer-reviewed publication and will co-present findings at the Scottish Heart Failure Nurse Forum meeting in November 2012.

### **Personal reflection on learning (David Barber, Heart Failure Nurse Specialist):**

Involvement in this project has given me an exciting and valuable development opportunity to collaborate with experienced researchers who share my interest in heart failure self-care; to build on my understanding of qualitative research; and to participate in all stages of an extensive systematic review. I have been able to gain insight into the principles and mechanisms involved in a rigorous systematic review, including quality appraisal of qualitative research findings.

Using a structured approach to qualitative data extraction I have been able to contribute to the process of categorising data and, with the support and supervision of other researchers, have

participated in thematic analysis. I have also had the opportunity to work with the Joanna Briggs Institute (JBI) database systems and have entered many of the findings into the software package. This gave me a good understanding of the principles involved in systematic review, and experience in navigating the software effectively to best manage large volumes of qualitative data.

In the latter stages of the project I have collaborated with the other researchers to develop good practice guidelines which will be disseminated to community-based practitioners involved in the management of heart failure patients. As a heart failure nurse practitioner I am well placed to share my learning experiences and project findings with other members of the multidisciplinary team, and through dissemination of identified good practice guidelines I hope to positively influence patient care.



## 11.0 FINANCIAL REPORT

<b>Salaries</b>			
<b>Staff Member</b>	<b>Time on the project</b>	<b>Role</b>	<b>Costs £</b>
Dr Kay Currie	In excess of 16 days	Project Leader	6,055
David Barber	15 days equivalent	Project Nurse	2,945
<b>Other Direct Costs</b>			
Miscellaneous: Printing, Postage/ phone calls etc.			100
Poster x2			100
Collaborator/Steering Group costs			55
<b>Total costs of Project</b>			<b>£9,255</b>

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## APPENDIX 1:

### Self- care needs in heart failure: Feedback from Scottish service users.

Dr Kay Currie, Glasgow Caledonian University, attended the heart failure patient forum meeting on 27<sup>th</sup> April to present findings and recommendations from a recent systematic review of qualitative evidence of the patient's perspective of self-care need in heart failure.

Following her presentation, forum members were given an opportunity to complete a feedback questionnaire to give their views on the proposed recommendations. Approximately 70 members attended the meeting and 34 usable questionnaires were returned, giving a response rate of almost 50%. The following points summarise the views of patient forum members:

#### 1. Our recommendations suggest health professionals should...

- ✓ Assess patients for problems that might affect their ability to organize their self-care, for example
    - Excessive tiredness / fatigue
    - Difficulty concentrating
    - Problems remembering to do things
    - Depression
- and should then tailor their advice to deal with these problems

##### Patient forum member responses:

- All 34 members agreed with this recommendation. Additional comments included;
  - *current services do not allocate time with patients to include this*
  - *sharing of good strategies to overcome this is more important*
  - *probably beneficial to patient only if consultant is totally competent in explaining the situation*
  - *A complex field; can HF nurses handle this?*
  - *this requires to be ongoing through the plan as these symptoms can radically change through the illness*

#### 2. Our recommendations suggest health professionals should...

- ✓ Provide easily understood information about all aspects of self care in heart failure
- ✓ Listen to patients to identify their priorities and daily challenges
- ✓ Check that patients understand the advice and share 'know how' ideas for daily life (drawn from suggestions other patients find helpful)

##### Patient forum member responses:

- 30 members agreed with this recommendation (4 did not provide a response)  
Additional comments included;
  - *heart failure nurses already do this*

- *One to one dialogue is critical*
- *Yes, I got guide/leaflet book with information in it but need to go over parts particularly relevant to each*
- *Self care =self management & self development i.e. need for on-line forums sharing information, practices and strategies*

**3. Our recommendations suggest health professionals should...**

- ✓ Involve carers (family or friends who provide help or support) in discussions about treatment if possible

Patient forum member responses;

- 24 members agreed with this recommendation; 3 suggested it would depend on the circumstances or patient preferences (7 did not provide a response). Additional comments included;
  - *This is very important as patient often unable to remember or concentrate on information given; (caregivers) often have insight into patients well-being*
  - *Depends on carer or family attitude*
  - *It may not be so easy for family & friends to support if they do not stay nearby*
  - *At present, as a carer, I feel I am intruding when I ask questions on his behalf*
  - *Agree, as they are unaware of symptoms and lack knowledge of condition and do not understand how to help*
  - *Yes and no – not everyone wishes or needs family & friends to be engaged in or with this process of illness/treatment – patient preferences must be observed at all times*

**4. Our recommendations suggest health professionals should...**

- ✓ Encourage people to get involved in support groups

Patient forum member responses;

- 25 members agreed with this recommendation; 3 suggested it would depend on the circumstances (6 did not provide a response). Additional comments included;
  - *If they have time. Each patient to be assessed individually if they want to be sociable!*
  - *A sharing of ideas and strategies always useful; also “you are not alone” state helps*
  - *Group are very limiting for me as I am fairly deaf*
  - *Yes, group is a good place to meet and see how others have coped and their experiences with other issues e.g. insurance, travel etc*
  - *Yes, but these could and should be on-line as well as physical & face to face*

## **APPENDIX 2: Steering Group Members:**

GCU Chair:	Prof Debbie Tolson
GCU Project Lead:	Dr Kay Currie
Service User:	Thelma Sneddon
QNIS representative:	Angie Henney
GCU Educational Lead:	Suzanne Bell
NHSGGC Lead Nurse:	John Carson
NHSGGC Project Nurse:	David Barber